National Mental Health and Learning Disability Nurse Directors Forum

Influencing and advancing care in mental health and learning disabilities

UK Learning Disability Consultant Nurse Network

People with a learning disability: COVID-19 planning and considerations for NHS Trusts.

All NHS Trusts providing specialist health services to people with a learning disability, have an important part to play in the ongoing fight against COVID-19.

Specialist community learning disability health services have significant reach and contact with large numbers of people with a learning disability, their families and social care services. Recent analysis[1] suggests across the UK, adult community learning disability teams, operated with a median caseload of 136, per 100,000 population, on March 31st 2019. This implies that collectively, in excess of 61,000 adults with a learning disability, or approximately 21% of those registered with their GP as having a learning disability, in England, are likely to be actively open to community teams at any given point in time. Of course the true population of people with a learning disability is known to be significantly higher, however community teams frequently operate according to an episode of care model which means they have knowledge, by virtue of previous contact, with many more people; and they are typically well acquainted with many of the health and social care services and user and family led organisations, that operate across their localities.

In other instances, Trusts will be supporting in excess of 1,100 people with a learning disability who have recently been reported[2] to be inpatients in, NHS provided learning disability / mental health hospital settings. Additionally, a similar number of people are currently in independent sectors inpatient settings, and will likely have some degree of ongoing contact with staff from NHS Trusts in the usual places of residence.

This planning framework has been developed to assist those charged with planning and coordinating local responses, to determine how specialist NHS health services for people with a learning disability can be applied with maximum effect and impact, during the unprecedented challenges associated with the current coronavirus outbreak and COVID-19.

It is recognised that some services and organisations may have systems and processes in place to inform planning, therefore decisions to implement the framework must be made by the organisation delivering the service and not by external organisations as part of a commissioning process.

[1] NHS Benchmarking Network (2020)
[2] NHS Digital Learning Disability Service Statistics (2020)

People with a learning disability and coronavirus

Some, though not all, people with a learning disability may have a heightened risk of contracting coronavirus due to factors such as residing in congregate settings, reliance on others for personal care and being supported by multiple care-givers, as well as barriers accessing preventative information and hygiene.

Also, some people with a learning disability who become infected, may be at heightened risk of suffering a particularly severe illness, due to other comorbid health conditions (especially those related to respiratory function, immune system function, heart disease or diabetes); treatment related factors, such as taking psychotropic medications which impact on respiratory or cardiac function; and, potential barriers in accessing healthcare.

As with general population, some people, although currently well, will be in need of stringent social distancing; and others who are at the highest risk of developing severe illness may be need a more prolonged period of 'shielding'. Supporting people with these measures, may pose significant challenges for some people with a learning disability, as well as their families and paid supporters. Some may struggle to understand and therefore fully comply with recommended infection control measures; whilst for others, usual daily routines may be grossly disrupted giving rise to significant anxiety and distress; and for some, usual supports may be disrupted where for instance, paid support staff are unavailable due to absences from work.

Where people become infected with coronavirus, develop active symptoms of COVID-19 and require treatment, either in their usual place of residence or in acute hospital settings, treatments may be particularly acutely anxiety provoking, or involve restrictions on individuals' autonomy with the aim of containing wider risks to public health and maximising the likely of a positive outcome. In order to ensure people's human rights are properly respected and protected, any restrictions on liberty should be demonstrably necessary, proportionate and applied in accordance with a clear legal process. Restrictions should be individually tailored, used as a last resort and should represent the least restrictive option to achieve a legitimate aim. This means that individual's risks should be clearly established and recorded and that wide ranging, proactive measures should be introduced to maximise wellbeing and people's understanding of the issues.

A planning framework.

This framework has been developed to support operational contingency planning and service delivery by specialist learning disabilities health services provided by NHS trusts. It may also be helpful in supporting broader strategic planning across localities, by commissioners, integrated care system leads etc.

The framework invites service leads to consider whether they have established appropriate coronavirus and COVID-19 contingencies across the full range and scope of circumstances of people with a learning disability who may require support during the current pandemic. This should involve recording and mapping existing plans for support by specialist learning disability services in relation to key areas for consideration for:

- People who are well and symptom free;
- Those who are symptomatic but remain and are being treated in their home / usual place of residence;
- Those who may require a transfer to an alternate setting for safe treatment of COVID-19 in conditions of isolation, or indeed admission to an acute hospital for critical care.; and
- Finally consideration should be given to support arrangements to those recovering from infection.

It is not intended to be prescriptive in how this framework should be used. In essence it provides a conceptual framework for planning, with the aim of ensuring that key areas are not inadvertently overlooked. Delivering robust responses will clearly require specialist learning disability services to work in full partnership with user led organisations, primary healthcare providers, local public health agencies and other secondary health providers, as well as third sector health and social care providers.

1. Supporting people who are well

Area to be considered	*Context of care and support*								
	Family home, with no external support	*Family home, with external support*	*Own home / tenancy, alone, with no external support*	*Shared home / tenancy, with no external support*	*Own home alone, with paid support*	*Shared home / tenancy, with paid support*	*Care home, without nursing*	*Care home, with nursing*	*Learning disability hospital*
Services need to identify those people for whom specific social factors are associated with a heightened risk of becoming infected by coronavirus: • This will include features of the living environment and home situation e.g. fragile support systems, congregate or overcrowded living environments, friends who actively discourages social distancing etc									
Services need to identify those people for whom specific personal factors are associated with a heightened risk of becoming infected by coronavirus: • Think about personal behaviours such as poor hygiene, spitting / biting behaviours etc • Also, impaired cognitive functioning, or features of the mental state, which obscure a person's ability to understand / follow advice. • Some people, despite social isolation, will have ongoing needs for continued treatment or health									

monitoring which means they continue to require routine contact with health services e.g. for outpatient treatment of conditions such as cancer; blood tests or other repeated investigations.									
Services need to identify people whose personal and health characteristics mean should they become infected, they are more likely to suffer a severe COVID-19 illness: • Take account of factors including: ○ Underlying health conditions e.g. diabetes, hypertension, respiratory conditions, cancer etc ○ Age ○ People's health status over the last 6 months and in particular any health conditions which they may not be fully recovered from ○ Also, treatment related factors such as: psychotropic medications which can suppress respiration or impact on cardiac function; drugs that lower immune response etc.									
Services need to ensure effective infection control arrangements within the home environment. • Extra attention should be paid to personal hygiene especially hand hygiene and not touching the face. • Considering how social distancing can be maintained.									

• Considering how shielding of those at heightened risk can be maintained. • Cleaning of home environments especially hard surfaces and touch points (handles etc).									
Individualised health surveillance approaches should be determined. • A range of basic daily health observations will be required. As a minimum, these will likely include monitoring temperature and respiration / breathing. ○ In other instances, such as settings where there is support from registered nurses, depending on the knowledge, skills and experience of those providing care and support, it may be also possible to also monitor things like oxygen saturation and blood pressure and to make use of National Early Warning Score (NEWS) 2 system. • Those undertaking any forms of health surveillance / monitoring will need to have clear routes of escalation (i.e. know exactly who to contact), in the event of any concerns.									
Services need to take steps to maintain / promote wellbeing amongst those who are currently well / asymptomatic: • Ensure hospital passports are in place and up to date and that people know where they are located. • For those able to engage with advance care planning and have knowledge of COVID-19, to be									

supported to advance care plan for if they contract the virus.
• People need access to good, accessible, up-to-date Information regarding COVID-19, how to stay safe, what testing may involve, what PPE is and why it is used etc. (For some, this might include anticipatory desensitisation to things like PPE).
• Social connectedness should be maximised e.g. through use of electronic video platforms, facility to send letters to family and friends etc. Some people may need advice and support to make use of new technologies.
• There may need to be emotional / psychological support to live with uncertainty, changed routines and disrupted support.
• For some, changes to usual routines may detract from well-established primary preventative strategies, in the context of PBS plans; and therefore alternate strategies may need to be planned.
• Actions should be considered to bolster people's immune systems:
  ○ Ensuring a nutritious dietary intake (food may need to be delivered)
  ○ Fluid
  ○ Exercise
  ○ Sleep
  ○ Stress reduction strategies
  ○ Encouraging smoking cessation									

○ Encouraging reduced alcohol intake and abstinence from illicit drugs and legal highs.									
Clear health protection plans should be established for the individual and where appropriate, for the household. • Usual support, care and treatment plans for wider needs may well need to be modified and care plans amended accordingly. • Those whose existing plans include restrictive interventions need to have the frequency, duration and intensity of use of those restrictions monitored with any increase being reviewed and responded to. • Plans should only include consideration of additional restrictions for the purposes of infection control, where these have been determined to be necessary and proportionate responses to risk factors described above; and can be shown to be a last resort, on the basis that all reasonably practicable steps in support of wellbeing have first been taken. • Escalation plans will need to identify contingencies in the event that social isolation cannot be maintained (possibly including arrangements for compulsory confinement under the provisions of the Coronavirus Act). • In some localities, in order to avoid unnecessary admission to critical care settings, escalation plans may include provision for confinement, for the purposes of infection control, of suspected or known COVID-19 cases with mild symptoms. This									

might include the use of hotel rooms, or previously decommissioned facilities within mental health / learning disability inpatient facilities.									
Support for the supporters • This will require good information to be available for family carers, paid supporters and professionals, so that they know what practical, personal and emotional support is available for them and how to access it.									

2. Supporting people who have symptoms – home care

	Context of care and support								
Area to be considered	*Family home, with no external support*	*Family home, with external support*	*Own home / tenancy, alone, with no external support*	*Shared home / tenancy, with no external support*	*Own home alone, with paid support*	*Shared home / tenancy, with paid support*	*Care home, without nursing*	*Care home, with nursing*	*Learning disability hospital*
Regardless of setting, strict infection control practices will be required. These need to include: • Safe arrangements for isolating people in their current / usual place of residence. • Accessible documents, pictures or videos regarding Personal Protective Equipment (PPE) may be helpful to address anxiety / fear.									

• Staff / carers will require access to PPE (and advice on use). ○ This may mean that health services need to be able to respond to requests from families or social care staff as to how PPE can be accessed. • There needs to be good information on handling and disposal of potentially contaminated waste, clothing, bed linen etc • Advice will be required regarding cleaning the environment (use of specialist cleaning products).									
Symptom monitoring will need to be maintained. The nature and extent of this will depend on the area where the person is being isolated and the knowledge and skills of those that provide support; but will likely include: • Breathing • Temperature • Fluid balance • Bowels • NEWS 2 ratings (in some, though not all, service settings) • Oxygen saturation levels (in some, though not all, service settings)									
Care and support needs, so far as possible, to alleviate of symptoms. • Needs to include clear arrangements for prescribing and administration of antipyretics. • Fluid intake needs to be encouraged.									

• There should be support and encouragement for rest, with possible consideration of posture in line with current medical recommendations. • Consider administration of passive oxygen at home or in hospital / care home settings, in line with current medical recommendations / advice.									
Escalation plans will be required for the following eventualities: • There should be pre-emptive acute hospital admission planning (including the development of up to date health / COVID passports and details as to how a person would be supported) in anticipation of: ○ Concerns arising from symptom monitoring ○ Increased breathlessness and respiratory distress ○ Increasing cyanosis ○ Increasing pryrexia ○ Diarrhoea ○ Changes in cognition / acute confusional states Escalation plans will also need to include individualised thresholds for stepping up to alternate models of care in the event that isolation cannot be safely maintained in the usual home setting.									
Usual support, care and treatment for wider needs will need to be modified.									
Support for the supporters. This will require good information to be available for family carers, paid supporters and professionals, so									

that they know what practical, personal and emotional support is available for them and how to access it.									

3. Acute hospital care

Area to be considered	*Context of care and support*								
	Family home, with no external support	*Family home, with external support*	*Own home / tenancy, alone, with no external support*	*Shared home / tenancy, with no external support*	*Own home alone, with paid support*	*Shared home / tenancy, with paid support*	*Care home, without nursing*	*Care home, with nursing*	*Learning disability hospital*
Hospital passports need to be up to date and available. • Brief, summary COVID-19 hospital passports may be helpful where people do not currently have one. (More likely where people live in own or family home). • Where person is admitted to hospital for critical care and does not have a hospital passport, community learning disability teams and / or acute liaison nurses may need to develop these as a matter of urgency in order to inform hospital care.									
Learning disability services need to provide effective liaison to acute / critical care colleagues.									

• Need agreed local contingencies if no acute liaison service is available. • Ensure if community services are in place, they link in with acute Trust staff.									
Isolation and Infection Prevention and Control measures • Ensure strict Infection prevention precautions in line with local COVID-19 policies • In the event of sufficient availability of PPE, it may be appropriate to consider in-reach support from social care provider or family member.									
Access to IMCAs will be required in many instances, to support decision making. • Best interest decision making is likely to be required where invasive ventilation is required • IMCAs will likely be involved in more wide ranging serious medical treatment decisions and where consideration is being given to 'Do Not Attempt Resuscitation' (DNAR) orders or withdrawal of artificially delivered nutrition and hydration (ANH). • Use of Court of Protection for urgent medical decisions where there is disagreement on best interests									

4. Recovering from COVID-19

Area to be considered	*Context of care and support*								
	Family home, with no external support	*Family home, with external support*	*Own home / tenancy, alone, with no external support*	*Shared home / tenancy, with no external support*	*Own home alone, with paid support*	*Shared home / tenancy, with paid support*	*Care home, without nursing*	*Care home, with nursing*	*Learning disability hospital*
Consideration needs to be given to immediate post-infection health needs including: • For those people admitted to hospital for critical care, planning should aim to support early, though clinically appropriate discharges. ○ The nature of care and support in the person's usual living environment will be important in ensuring early discharges. • Many people will require ongoing, post-infection health monitoring. • Recovery will need continuing support to ensure an appropriate balance of rest and activity; and adequate food and fluid intake, • For some, there may be ongoing coronavirus related treatments such as specific exercise regimes or medications.									
There may need to be recognition and support in relation to longer term sequelae such as: • Any long term respiratory or cardiac complications • Post viral fatigue									

There may need to be emotional / psychological support for people and those that support them, concerning trauma associated with serious illness and possible hospital admission. Considerations include: • ICU Psychosis or trauma, if ventilated. • Potential complications associated with long term ventilation (mobility for example). • New drugs which may need to be continued after recovery. • Long term effects of separation / isolation from those who know the person well (family carers). • The impact of experiencing or witnessing invasive procedures and other traumatic events, such as death of other patients. • Important therapeutic relationships with professionals may have qualitatively changes as a result of changes to care before and during illness. Consideration may need to be giving to repairing / rebuilding these relationships.									
Support for the supporters. This will require good information to be available for family carers, paid supporters and professionals, so that they know what practical, personal and emotional support is available for them and how to access it.									